

# NZCCR REPORT 2016

The New Zealand Children's Cancer Registry (NZCCR) holds verified diagnostic, demographic and treatment information for children diagnosed with cancer since the year 2000.

The NZCCR Working Group, under the governance of the National Child Cancer Network, is responsible for monitoring the ongoing collection of registry data to support New Zealand childhood cancer research.

2016 has been another busy one for the NZCCR Working Group as we endeavor to increase the profile of the registry and make further enhancements to our registration practices. This report highlights some of our recent activities and provides a snapshot of the children who were diagnosed with cancer in 2016.

## ADOLESCENT AND YOUNG ADULT CANCER RESEARCH

This year saw the publication of our 2000-2009 adolescent and young adult (AYA) incidence and survival analysis in the Journal of AYA Oncology. This piece of research directly followed on from our earlier analysis of childhood cancer incidence and survival and supported the establishment of the AYA Cancer Network Aotearoa.

## CONFERENCE PRESENTATIONS

In April 2016 I was awarded a scholarship by the William Rudder Memorial Fund to represent the NZCCR at the Asia-Pacific Cancer Leaders Summit held in Brisbane. Two of our abstracts were accepted for presentation; one describing the unique integration of the NZCCR with the Late Effects clinical database and a second on the development of a Pacific Children's Cancer Registry.

In October Dr Jane Skeen gave an oral presentation at the International Society of Paediatric Oncology Congress in Dublin describing the NZCCR's collaboration with the NZ Cancer Registry to assess the accuracy and completeness of our 2010-2014 child cancer registrations. New Zealand is unique in having the opportunity to undertake such verification activities and we were pleased to report that both registries performed well on all measures of data quality.

## PAEDIATRIC CANCER STAGING PILOT STUDY

In late 2016 we were invited to participate in an international pilot of an web-based application which the Australian Paediatric Cancer Registry are developing to support consistent paediatric cancer staging by cancer registries.

As part of a University of Otago Summer Studentship (kindly sponsored by the Children's Cancer Research Trust) Danny Nam undertook a review of the staging information held by the NZCCR for all Christchurch-based patients and staged these cancers according to the newly published Toronto Paediatric Cancer Staging Guidelines using the online application. Danny was able to provide valuable feedback to the Australian app developers and fill a number of staging gaps in the NZCCR. The NZCCR Working Group is currently reviewing our staging information to ensure that it is both consistent with these new international guidelines and continues to meet the needs of clinicians delivering patient follow-up care.

## COMMUNICATION WITH FAMILIES

In 2016 we modified the NZCCR family information sheet so that it better addresses the common questions which families ask us about the registry. This includes how the NZCCR and the NZ Cancer Registry differ, what information we share, and why a separate registry for paediatric cancers is needed. We also published a brief piece in the Child Cancer Foundation newsletter to explain more about how the NZCCR functions from both an individual patient and national perspective.

If you have any questions about the registry or wish to find out more about how to request registry data, please visit the NCCN website [www.childcancernetwork.org.nz](http://www.childcancernetwork.org.nz) or contact me at [kirsten.ballantine@cdhb.health.nz](mailto:kirsten.ballantine@cdhb.health.nz)

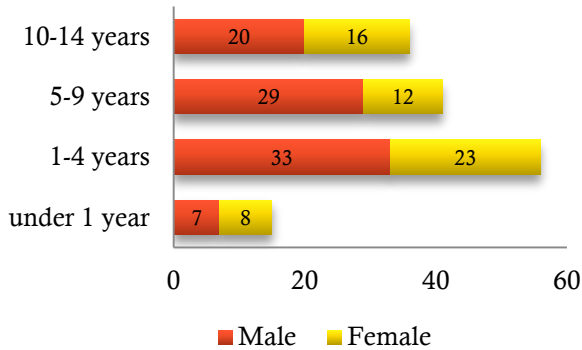
Kirsten Ballantine  
NZCCR Manager / Analyst  
on behalf of the NZCCR Working Group.

# NZCCR SNAPSHOT 2016

Note: this snapshot relates to New Zealand children aged 0-14 years newly **diagnosed with cancer** in 2016. It does not include patients referred to our paediatric oncology centres from overseas, those who are aged 15 years and over, or children who are diagnosed with a non-malignant/other haematological condition. As many childhood cancers require several years of treatment, the number of patients **undergoing treatment** each year is significantly higher.

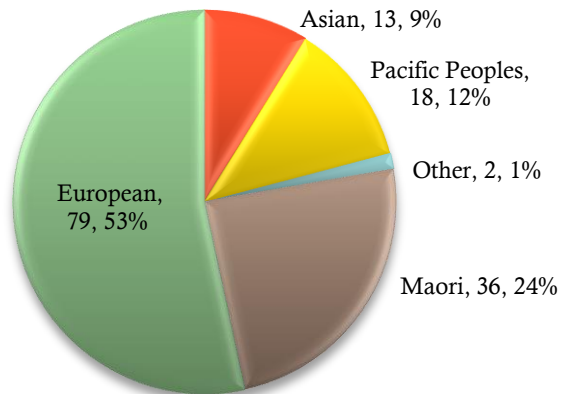
## AGE AND GENDER

148 children under the age of 15 were diagnosed with cancer in 2016. 55 of these children (37%) participated in an international collaborative clinical trial, a 6% increase on 2015 enrolments. This year, there were many more boys (89, 60%) than girls (59, 40%).



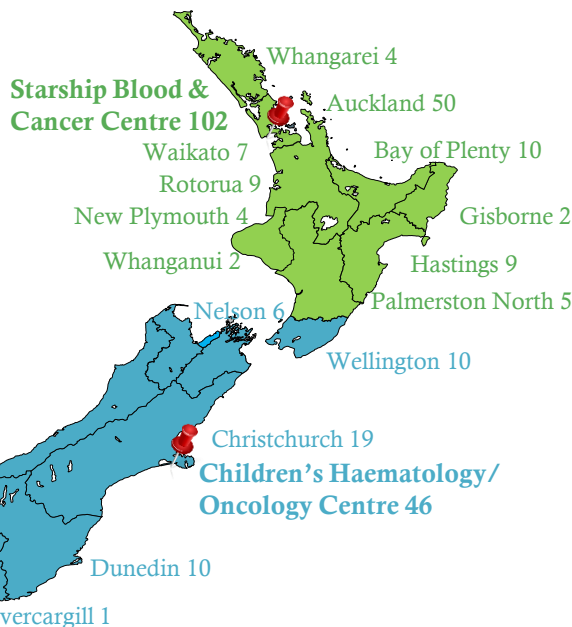
## ETHNICITY

By prioritised ethnicity, 24% of children diagnosed in 2016 were Maori, 12% Pacific Peoples, 9% Asian, 2% African/Middle Eastern, and 53% NZ European/Other European.



## SHARED CARE CENTRE

102 of the children diagnosed with cancer in 2016 were referred to Starship Blood and Cancer Centre and 46 to the Children's Haematology and Oncology Centre (CHOC). There are considerable year on year fluctuations in patient numbers by region. Registrations from Dunedin, Rotorua and Hastings were noticeably up on 2015 numbers.



## DIAGNOSTIC GROUP

Paediatric blood cancers – leukaemias and lymphomas - accounted for 53% of all new cases in 2016. Neuroblastoma and acute leukaemias were more commonly diagnosed in children under the age of five while all new bone tumour cases were diagnosed in children over the age of 10.

